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A Psychoeducational Support Group for Family Caregivers of Elders with Major Neurocognitive Disorder/ Dementia

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Abstract

Background: Dementia is a major public health problem impacting an estimated 65.7 million people worldwide by 2030. It primarily occurs in the elderly population (over age 65) and also affects family caregivers, who often experience significant stress and burden. A psychoeducational support group may be an easy and cost-effective solution to caregiver stress and financial burden.

Objective: To determine whether or not there is an effect on self-reported stress and burden on family caregivers of elders with dementia (EWD) of a voluntary psychoeducational support group in the setting of Assisted Living, Memory Support, and Skilled Nursing led by a psychiatric nurse practitioner.

Method: Design of the project is Quasi-experimental, pre-test/ post-test with convenience sampling and voluntary participation. The study only included family members of EWD who are living in an Assisted Living, Memory Support or a Skilled Nursing unit. There will be three psycho-educational support groups over seven weeks. The assessment of stress will be based on the Kingston Caregiver Stress Scale (KCSS) and burden will be based on the Zarit Burden Interview- short form (ZBI-12).

Results: The average scores on the KCSS and ZBI-12 decreased from the beginning to the end of the intervention. There is a correlation between the number of years as a caregiver and the amount of decrease in symptoms.

Implications: A support group may prove to be a low-cost intervention to decrease stress and burden in family caregivers and allow family caregivers to improve their quality of life while decreasing costs.

Keywords: Elderly, dementia, caregiver, psychoeducational support group, quality of life, burden, stress

Psychoeducational Support Group for Family Caregivers of Elders with Dementia

Dementia is a worldwide major health problem. According to the Alzheimer's Association website (2018), "One in three seniors dies with Alzheimer's or another dementia" and "Alzheimer's Disease kills more seniors than breast cancer and prostate cancer combined." Alzheimer's Disease is the most common form of dementia. Dementia is an illness that does not discriminate and can affect anyone.

Whether an EWD is living with a family caregiver in the community or is in a long-term care or assisted living facility, caregiver stress may still exist. The research does not discriminate between stress in families which have family members living in the community or in facilities. Even though the EWD may be in a facility, family caregivers have other roles including decision making on their behalf, end of life planning, transporting to appointments, managing money, dealing with everyday life stress such as phone calls and doctor visits, participating in feeding, and engaging their family member in activities. Family caregivers may not be at the bedside, but they still meet the criteria of "caregiving," and feel the resultant stress and burden (Whitlatch & Orsulic-Jeras, 2016). Only EWD who live in an Assisted Living, Memory Support, or Skilled Nursing unit are included in this study. The EWD can have irrational behaviors, paranoia, anger, withdrawal, poor self-care, and insomnia which contribute to caregiver stress and burden. As the caregiver is often working or struggling to make ends meet there are financial burdens, emotional issues, physical health problems, and other challenges such as guilt and exhaustion in supporting someone with cognitive impairment. This can lead to decreased work participation, decreased contributions to retirement accounts, and increased health care costs. These costs to society effect everyone.

Many EWD are being cared for by family members. "Sixteen point one million Americans provide unpaid care for people with Alzheimer's or other dementias. In 2017 these caregivers provided an estimated 18.4 billion hours of care valued at over $232 billion (Alzheimer's Association, 2018). This includes family member of EWD who are living in facilities as well as those living in the community.

Dementia takes a physical toll on caregivers. "Compared with non-caregivers, caregivers of EWD experience worse physical health outcomes in terms of poorer results on objective physiological indicators, self-reported health status and health behaviors" (Chua & Pachana, 2016, p. 3). There are also other effects that lead to poor health outcomes for caregivers. "Many studies have shown that caring for a person with dementia can have negative effect on a caregiver's physical, psychological or emotional health, social life, and economy as defined as caregiver's burden" (Signe & Elmstahl, 2008, p. 98). This holds true throughout the research whether the EWD lives in a facility or in the community.

This research measures the effect (if any) of a psychoeducational support group on self-reported stress and burden for family caregivers. "As the disabilities and care needs of the older adult with dementia increase over time, the informal caregivers play a key role in the delivery of this healthcare worldwide…Participation in support groups provides a meaningful improvement in the wellbeing of the informal caregiver" (Lauritzen, Pederson & Bjerrum, 2013, p. 33). Decreasing stress and burden in family caregivers is important because it can affect the quality of life. In this project, the definition of quality of life means a life with less stress and burden where people feel happier, are able to engage in social activities and relationships, feel more energetic, and spend less time worrying. According to Zarit, Reever and Bach-Peterson (1980), burden is defined as a multidimensional response to physical, psychological, emotional, social

and financial stressors associated with the caregiving experience, and is the definition used in this study.

This research took place at a continuing care retirement community (CCRC) in the Pacific Northwest. While the residents who have dementia are cared for by staff on the Assisted Living, Memory Support and Skilled Nursing units, the family members still play a large role as caregivers. In this capacity, caregivers generally do not receive peer support or support from the healthcare team, unless they seek individual therapy or counseling. This experimental psychoeducational support group offered a unique opportunity to gain peer support from other family caretakers who may struggle with similar issues and stresses. This study will examine if a psychoeducational group can assist family members of EWD. Research will be presented in the Literature Review which demonstrates there are some completed studies on the effectiveness of a Psychoeducational Support group to assist family caregivers of EWD. These studies are limited in number and in replicability.

Problem Statement

Research demonstrates that family caretakers of EWD have increased rates of stress and feel higher burden. This can lead to negative medical and psychological consequences for the caregiver. Decreased stress can improve quality of life and reverse the medical and psychological issues that may have developed for the family member of an EWD who lives in an Assisted living, Memory Support, or Skilled Nursing unit.

Research Question

Can a psycho-educational support group change self-reported stress and burden in family caretakers of EWD? This project will assess a sample of family caregivers from Assisted Living, Memory Support, and a Skilled Nursing Facility in a CCRC to assess rates of family caregiver stress and burden before and after a psycho-educational support group intervention developed and facilitated by a psychiatric nurse practitioner If this intervention demonstrates efficacy in decreasing caregiver burden and stress, a psycho-educational support group may be a cost and time efficient method to promote health in caregivers and decrease medical and psychological costs of caregiving.

Theoretical Framework

From the time of Florence Nightingale, the goal of nursing has remained unchanged: "Namely to provide a safe and caring environment that promotes patient health and wellbeing" (Selanders & Crane, 2012). Yet, the way to define "care" or a "caring environment" is elusive. This project follows a model of caring which is guided by Swanson's Theory of Caring. (Swanson, 1991). This theory identifies five essential categories that characterize caring and include: knowing, being with, doing for, enabling, and maintaining belief. These classifications apply to caregiver stress and burden in family caregivers of elders with dementia. The first category, "knowing," is a stage where the care giver recognizes that a family member does have dementia. The second stage, "being with," is where the family caregiver takes on the role of caregiving and devotes time and energy into caring for their family member. In the next stage, "doing for," the participants seek out professional assistance in an attempt to improve their own practices for the family member. In the next stage of "enabling," the family caregivers engage in methods that enable themselves to live a life with less stress and burden. Finally, in the last stage,

"maintaining belief," the group members support each other so that they can maintain the belief that caregiving for a family member with dementia can be rewarding and doesn't always have to be stressful. Swanson's Framework of Caring provides a lens through which caregiving can be viewed as nuanced with different levels and stages in the caring experience. The following literature review will evaluate how family caregivers of EWD are affected by a psychoeducational support group.

Review of the Literature

CINAHL and Google Scholar were searched using the following limitations: English language only, human subjects, years 2008-2019 The following MeSH terms were used: dementia, caregivers, family, support, cognitive impairment, stress, burden, quality of life, depression, isolation. Hundreds of articles were retrieved, including systematic reviews, original research, case studies, and secondary reviews of the literature. After sorting through and identifying articles that were relevant to the proposed intervention, 13 articles were included in this initial literature review. The data demonstrates that while there is some support for the efficacy of a psychoeducational support group for family caregivers of elders with dementia, whether they are living in a facility or in the community, there is a need for more research.

Role of Caregivers

The amount of care that a person with dementia requires varies depending on the severity of the cognitive impairment. Some elders require placement in an assisted living or long-term care facility while others are cared for at home. In many cases, family caretakers may be responsible for helping with activities of daily living (ADLs) such as bathing, toileting, and eating or they might be more depended on for Independent Activities of Daily Living (IADLS)

like managing money, cleaning, and cooking. "The majority of people with dementia live in the community (estimated to be between 70%-81%) and for approximately 75% of these people, care is provided by family and friends" (Brodaty & Donkin, 2009, p. 217).

For family members caring for EWD there can be stigma, fear, and confusion as to what is happening, and what will happen next. "In addition to not knowing what types of supports exist, families face many challenges to receiving this desperately needed education and support" (Whitlatch & Orsulic-Jeras, 2017, p. 9). Barriers may include not knowing where to go for resources or not being able to physically get the elder into the car. EWD may have disruptive behaviors, and caregiving can be fatiguing. "Dementia is associated with long care hours and physically demanding caregiving" (Brodaty & Donkin, 2009, p. 218).

Devoted family members often make sacrifices in other aspects of their life. "Caregivers face many obstacles as they balance caregiving with other demands including child-rearing, career, and relationships. They are at increased risk for burden, stress, depression, and a variety of other health complications" (Brodaty & Donkin, 2009, p. 218).

The personal sacrifices made by caregivers, including isolation and stress, can have consequences for their personal health.

> Dementia caregivers are at an increased risk for various health problems including cardiovascular problems, lower immunity, poor immune response to vaccine, slower wound healing, higher levels of chronic conditions (such as diabetes, arthritis, ulcers and anemia), more doctor visits and use of prescription medications, poorer self-rated health, decreased engagement in preventative health behaviors such as exercise, and greater

likelihood of smoking, drinking alcohol, and poor sleep patterns. (Brodaty & Donkin, 2009, p. 222).

One might think that these issues in caregivers only occur when the burden is extremely heavy as with an elder with severe dementia, but, in reality, family caregiver associated stress can occur with any level of dementia and with any level of care. "The measure of the perceived burden is not solely dependent on the severity of the disease but is also related to the closeness of the caregiver to the person with the disease" (Morrow-Odom & Robbins, 2012, p. 83). Therefore, family caregivers who feel more emotionally connected to their EWD may perceive more burden.

Needs of Caregivers

"Levels of psychological distress and stress are significantly higher, and levels of self-efficacy, subjective well-being, and physical health significantly lower in dementia caregivers than in other caregivers; these differences are even larger when compared to non-caregivers" (Brodaty & Donkin, 2009, p. 219). Family caregivers of elders with dementia have psychological and physical needs that are different than the needs of other caretakers and of other adults who are not caretakers and therefore require unique interventions, like a psychoeducational group tailored just to caregivers of EWD.

Family members also have educational needs based on the course of dementia, expected behaviors, treatments, end of life issues, and community resources available. "Other types of information that are useful for individuals living with dementia and care partners address the future care needs of the individual, and decision making around how these needs will be met as the disease progresses" (Whitlatch & Orsulic-Jeras, 2016, p. 61).

Another need for family caregivers is socialization. Being a caretaker can promote isolation from friends and community because taking care of an elder with dementia can be time and energy consuming. "Support groups encourage care partners and individuals living with dementia to share personal experiences and learn from others, while fostering engagement and socialization" (Whitlatch & Orsulic-Jeras, 2016, p. 60). A support group can decrease caregivers' sense of isolation and promote interaction with peers and community.

Other needs identified have included counseling and respite. "Families report positive outcomes from their experiences meeting individually with counselors, social workers and other clinicians who provide individual, didactic and family counseling, and/or psychotherapy (Whitlatch & Orsulic-Jeras, 2016, p. 60). Counseling can help deal with interpersonal stress, anger, depression, anxiety, and other mental health concerns that may arise. Sometimes the family caregiver may just need a short break, and in this scenario, respite may be indicated. During this time the caregiver takes a break while another family member, friend, caregiver, or an adult day program cares for the elder. Often a respite break can help the caregiver to recharge and rejuvenate (Whitlatch & Orsulic-Jeras, 2016, p. 61).

A study by Ducharme et al. (2014) studied the needs of family caregivers of people with early onset (before the age of 65) dementia. The top four identified needs included:

> (1) To receive more information on available help and financial resources; (2) to have their relative feel valued as persons and to offer them stimulating activities adjusted to their residual abilities; (3) to reduce stress stemming from their caregiver role assumed at an early age and to have the chance to enjoy more time for themselves and; (4) to receive help at the right time and for the help to be tailored to their situation of caregiver (p. 1

While these priorities are tailored to a caregiver for a person with early onset dementia, they hold true for the elderly as well. Caregivers for the elderly also need help with financial resources, feeling valued, dealing with stress, and having personal time (Ducharme et al., 2014).

At every stage of dementia, it is important to implement a multi-disciplinary approach (Whitlatch & Orsulic-Jeras, 2016). The early stages may be full of fear for the future. The elder may only have minimal deficits. It may be important to examine plans for the future and end of life preparation while the elder can still participate. At this stage, a support group to meet peers and learn about resources could be important.

As the illness progresses to middle stage, the caregiver continues to have educational and support needs which could benefit from a support group, but the needs also change because the elder needs more help with ADLs and IADLs. "The increasing dependence of the individual for help with IADLs and ADLs often brings about higher levels of stress and burden for the caregiver" (Whitlatch & Orsulic-Jeras, 2016, p. 63). At the late stages of dementia, the caregiver needs include peer support and psychoeducation as the elder with dementia possibly transitions to palliative care or placement in a Memory Support or Long-Term Care facility.

While the different needs of the family caregiver at each stage of dementia can be articulated, it is important to realize that each caretaker has unique needs. "The individuality of each person in the support group is highlighted by the unique situation and burdens experienced even though they are all caring for someone with the same diagnosis" (Morrow-Odom & Robbins, 2012, p. 79). For this reason, a psychoeducational group for all family caretakers for elders with all stages of dementia will allow for family caregivers to relate to each other and support each other through different stages and may prove an effective intervention

Effectiveness of Support Groups

Several studies have been conducted to evaluate the effectiveness of a psychoeducational support group to decrease self-reported stress and burden in family caregivers of elders with dementia. Wang, Chien, and Lee (2012) tested the effectiveness of a 12-week support group for Chinese family caretakers for elders with dementia in Hong Kong. This randomized controlled trial included 78 families, 39 in the experimental group, who took part in a psychosocial support group run by a psychiatric ARNP. The results showed an improved quality of life and decreased distress compared to routine mental health care (which may include counseling). This study was particularly interesting because it focused on the Chinese population, where the culture brings an obligation to care for elders in the home (Wang, Chien & Lee, 2012, p. 211).

Another study assessing an Asian culture, implemented by Lee and Yim (2013), took a qualitative approach to examining the experience of a psychoeducational support group for family caregiver of elders with dementia in Korean American culture. Seven Korean American families were involved in the group. Emerging themes included "Importance of education about dementia, social support from other Korean caregivers, role of language and Korean culture, heterogeneity of caregivers needs with regard to stages of disease, and relationship with care receivers" (Lee & Yim, 2013, p. 13). This investigation was focused to identify cultural issues that would change the effectiveness of the group. The identified themes showed that a psychoeducational support group can be effective, and possibly even more so if it is tailored to the Korean American culture. "The qualitative findings indicate that most of the participants found the psychoeducational support group to be valuable because of the acquired social support and the useful information gained from caregivers" (Lee & Yim, 2013, p. 23). Since the group support sessions were conducted in the Korean language, it made the participants feel more

comfortable: "The experience of participating Korean-American dementia family caregivers in the culturally competent psychoeducational group provides valuable implications for group work practice with other Asian immigrant family caregivers" (Lee & Yim, 2013, p. 24). The unique experience of being Korean American and having an elder family member with dementia may respond well to group psychoeducation and support.

In addition to cultural differences effecting the group process, a systematic review conducted by Lauritzen et al. (2013) looked at the effectiveness of a psychoeducational support group for family members of elders with dementia living at home in urban areas compared to rural areas. "Current research shows that support groups are considered an especially economical way to relieve informal caregivers stress and burden" (Lauritzen et al., 2013, p. 33). In addition, this review examines whether support groups are equally as effective in urban populations as they are in rural populations:

> Informal caregivers in urban and rural settings experience different stressors. In rural settings the informal caregivers might have a higher level of negative mental impact, a limited use of respite care, and a higher participation rate in support groups. Whereas informal caregivers in urban settings might have a higher level of social isolation, a higher use of respite care, and limited participation in support groups (Lauritzen et al., 2013, p. 34).

The evidence behind higher participation in rural areas is not clear, it may be because there are less resources to choose from in rural areas. Whatever the case is, it is yet to be determined if caretakers of elders with dementia fare better in rural or urban areas.

Reducing caregiver burden and self-reported stress is the main purpose of the psychoeducation support group intervention contemplated by this research. A pilot study done in 2008 studied the level of stress in a group of 312 caregivers, 158 in the experimental group, over a course of five weeks of psychoeducation group and then a conversational group every other week for three months. They were also assessed six months out. This was a randomized controlled study. The group had positive effects on burden at 5 weeks and the results persisted at 6 months. The best effects were noted in caregivers who had poor physical health, which demonstrates the need to get caregivers enrolled in a group as early in the course of dementia as possible. This particular study focused on family where the EWD is living in a facility.

In a Swiss mixed-method study to evaluate the feasibility and possible outcomes from a psychoeducational support group on caregivers' health, the group resulted in "Substantial and significant improvements in burden ($d = 0.41$, $p < .05$), psychological distress ($d = 0.54$, $p < .05$) and self-efficacy ($d = 0.43$, $p < .05$). The qualitative results emphasized the benefits of a group format: Participants felt understood by peers, could build new social bonds and experienced reduced social isolation" (Pihet, Kipfer, 2018, p. 209). The study focused on coping with the daily stress of dementia, with the assumption that caregivers can help better if they feel better (Pihet, Kipfer, 2018). This study assessed burden using the Zarit Burden Interview. The same tool that this researcher used.

While these results are significant, some family caregivers are logistically unable get to a support group. A Quasi-experimental study was done by Chua and Pachana (2016) to see if a psychoeducational DVD could decrease stress in Chinese Australian and Singaporean family caregivers of elders with dementia. This study included 12 caretakers and followed an 8-week program based on a DVD. The results were positive but not robust and aimed to increase

coping. Coping and psychological distress were measured at baseline, mid-point, and post-intervention. By the end of the intervention caregivers reported fewer problematic behaviors, but there was no change in caregiver anxiety, depression or worry. This lack of change in caregiver emotions is important to consider because it may be comparable to changes identified after the psychoeducational support group being studied. Because the DVD is lacking the aspect of the social interaction, it may not have been as effective as the group setting.

Project Design

Institutional Review Board

This researcher gained approval from the Institutional Review Board (IRB) at Seattle University. The CCRC does not have an IRB.

Participants

The participants were selected by convenience sampling. The group aim was to have at least ten members and no more than twenty. The final group consisted of seven participants. Locator signs were placed in the elevators of the Health Center with the researcher's contact information. Also, a monthly email to all family members of residents in the CCRC included information about the group. The plan was for the first twenty responders to be included in the group. All contact was initiated by the interested family caregiver. Inclusion/exclusion criteria state that the participants must be at least 21 years old, must read, write, and speak English, and must have a family member with dementia living at the CCRC. The participants signed informed consent forms during the first meeting of the group and can withdraw from the study at any

point. Information on continued mental health support in the community was available. There were non-alcoholic drinks and snacks, but no financial incentives for participation.

Data Collection

The participants orally consented to participation as a group. Identifying demographic data collected included age, gender, race, education level, and number of years as caregiver. This information was used to identify if certain groups have a different response to the intervention. The assessments were filled out with paper and pen. Everyone in the group filled them out before the first group and after the last group; it took about 10 minutes. A 95% response rate was anticipated and reached.

Content of Group Intervention

There were three 90-minute sessions. The group was held in the early evening hours to accommodate caregivers who needed to come after work. Confidentiality was discussed, and group members each verbalized their commitment to not sharing any personal information that was discussed during the group outside of the group. During the first session the members had a chance to introduce themselves and state why they have chosen to come to the group. They shared what stage of dementia their family member was in. The theme for the first session was balance, discussing with caregivers how to establish balance of caring for themselves and their loved ones (session outline seen in Appendix G). There was time for group discussion after the didactic session.

The second session started by allowing for discussion of any strategies learned from the first session and their effectiveness. Then, during the second session, the facilitator taught on management of memory loss and difficult behaviors. Some points that were covered include

medication, adult day health, assisted living/long-term care placement, occupational, physical, and speech therapy, and other strategies (see Appendix G for outline of session). Group members then had the opportunity to share their unique experiences in a discussion format.

During the third and final session the facilitator described the progression of dementia and attempted to alleviate some fears about disease progression and what is to come. Education on end of life planning as well as information on dementia resources was provided (see Appendix G). After the teaching, group members had the opportunity to bring up fears and concerns. To conclude, the participants shared any changes in their life that they have noticed since attending this group and they had the opportunity to ask questions. Before leaving they filled out measures assessing stress and burden.

Methodology

This study used a Quasi-experimental pre-test/post-test design. The purpose was to examine self-reported stress (measured with the KCSS) and burden (measured with the ZBI-12) before and after participation in the psychoeducational support group. There were three 90-minute sessions, and the surveys were filled out on site before the first and after the last session. The psycho-educational support sessions (see Appendix G for an outline of the sessions) were designed based on scientific evidence that identified the needs of family caregivers and allowed time for peer support (Alzheimer's Association, 2018). The group was organized and facilitated by a Psychiatric ARNP.

Setting

This study took place at a CCRC in the Pacific Northwest. The group met in a conference room.

Tools

The assessment tools used for this intervention are the Kingston Caregiver Stress Scale (KCSS) and the Zarit burden Interview- short form (ZBI-12). Both assessments are available online for free for research. The instruments have been broadly assessed and found to be reliable in a multitude of settings; they can be used to evaluate stress and burden for caregivers of people living in the community or in a facility. Both scales are applicable to family members who are caregivers for loved ones with dementia. The KCSS was used to assess self-reported stress (see Appendix A). The self-assessment is divided into three topics which are encompassed by 10 questions. The three domains include caregiver related feelings, family matters, and financial health The degree of stress is rated on a 1-5 scale; the scores are ordinal.

According to Sadak et al. (2017), there is a high degree of internal reliability with an alpha coefficient of 0.88. Because there are subgroups of rating scales (caregiver related feelings, family matters, financial), which may differ with respect to internal consistency, the alpha coefficient was determined for each of the sub-scales and is: care group: 0.85, family group: 0.75, financial: unable to determine with only one question. There is reliability not only in the entire survey, but also within each sub-group of questions.

Another survey, the Zarit Burden Interview-12 was used to assess burden (see Appendix B). The ZBI-12 is a twelve-item scale for dementia caregivers to rate their depressive symptoms, overall health, and care recipient's physical functioning and behavioral problems. According to Tang et al. (2016) "ZBI-short demonstrated satisfactory internal consistency and concurrent validity" (p. 998). Content validity was established by interventionists, project advisors, and investigators who assessed whether the ZBI-12 was relevant to caregiver burden

and suitable to older caretakers in terms of acceptability and readability. The panel agreed that the scale showed adequate content validity.

Among a group of Hong Kong Chinese dementia family caregivers, the ZBI-12 demonstrated internal reliability with an alpha coefficient of 0.84 (Tang et al., 2016). There were consistent correlations between depressive symptoms, self-rated health, care recipients' physical functioning, and disruptive behaviors.

Financial analysis, feasibility

There was be no cost for use of this facility or recruitment of subjects. Both assessment tools were available free of cost for research. The cost of drinks, snacks, and supplies was minimal).

Analysis

This researcher examined the results of the KCSS and the ZBI-12 and analyzed it using a paired T-test. Data was entered into a spreadsheet, so the researcher was able to identify trends. Trends were identified from the demographic data which was collected.

Timeline

The recruitment started in December 2018 (following IRB approval) and the first group met in January 2019. There were three 90-minute group sessions, held every other week in the late afternoon/evening. Assessments (KCSS and ZBI-12) took place before the first group and after the last. See Appendix F for Gannt chart.

Results

There were six participants who attended all three psycho-educational groups and completed the KCSS and ZBI-12 before and after the intervention. There was one participant who attended the first group and filled out the initial survey but did not attend the other groups or fill out the post-surveys. The group consisted of all Caucasian women between the ages 55-85. All had an education of at least some college, with five out of six having graduated from college and two having obtained a post-graduate degree. All participants have identified as a caregiver for at least one year, with one participant having been a caregiver for six or more years.

Both surveys showed a decrease in stress and burden from pre-intervention to post-intervention (7 weeks). The data that was collected demonstrates a trend with years of caregiving; the longer the person has identified as a caregiver, the greater reduction in self-reported stress and burden. There may be confounding variables, but the participants did not discuss any other supports that they started during the time period of the group, so it appears that the group had some positive impact. The identified trends in data analysis held true for the KCSS and the ZBI-12.

One explanation for this trend may be that those who have been caregiving longer did not realize how stressed they were because they had been doing it so long. The group helped them realize that they really are extremely stressed and after the group they felt less stressed because they started to pay attention to their emotions and take better care of themselves. No correlation was found between age and level of self-identified stress or burden. In this study, educational level also did not relate to level of self-identified stress or burden.

Discussion

Limitations

The data that was collected and the collection process demonstrates a limitation because all of the participants were Caucasian women. This was not intended, as the participants were recruited through convenience sampling. Also, in this particular CCRC, the population was relatively affluent with high socio-economic status.

Because this project was limited to family caretakers for elders who are living in assisted living, memory support, or skilled nursing units, family caretakers living in the community might respond differently to the intervention. Also, further research might assess if ongoing peer support for family members beyond the time period of this intervention could be useful. Also, people speaking English as a second language, mixed gender and non-binary groups, races, ethnicities, educational levels, and cultural affiliation may all affect the outcome of this small study. This sample size is too small to be generalizable and more research with a larger sample size is indicated (in this study n=6). The fact that the caregivers in this study do not have the burden of physically caring for their family member might add or subtract from self-reported stress and burden.

Significance and Implications

A three-session group may effectively decrease family caregiver's stress and burden. It may be an easy and cost-effective way to improve quality of life and decrease healthcare costs for family members of elders with dementia, a population that is currently growing. The psychoeducational group can be implemented at this continuing care retirement community (CCRC) and in other facilities that care for elders or in the community. Research could be

disseminated with presentations to the community or to groups for elders. Results could be published in the newsletter for the CCRC which is distributed in the greater Seattle area as well as in a professional journal that focuses on gerontology and elder care.

This small study, while not definitive, adds to the literature. More studies adding more data that is specific and replicable are needed. The cultural aspect of psychoeducation and group support may also be interesting to examine. Families of different cultures, races, and socioeconomic classes may experience the stress and burden of caregiving differently. Importantly, money saved from decreased stress and burden in caregivers is significant. Adding support may decrease wage loss and missed work. Less money may be spent on physical and psychological consequences that effect family caregivers due to stress and burden. "Ten million caregivers age 50+ who care for their parents lose an estimated $3 trillion in wages, pensions, retirement funds and benefits" (MetLife Mature Market Institute, 2011). With further study, a psychoeducation support group may be determinative in decreasing costs.

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APPENDIX A

Kingston Caregiver Stress Scale (KCSS)

Providence Care

Case #: _____

Relation to Patient_____Date:_____

KINGSTON SCALES

Lives in: Community____ Long Term Care Facility____Other ____

Some people report feelings of stress surrounding certain aspects of care giving. To what extent, if any, do these apply to you in your role of care giving to your spouse or relative? Using a 5 point rating scale, where 1 equals no stress and 5 equals extreme stress, indicate the extent of the stress or frustration you feel surrounding the following issues.

1	*2*	*3*	*4*	*5*
Feeling NO Stress (Coping fine, no problems)	***Some Stress***	***Moderate Stress***	***A lot of Stress***	***Extreme Stress (Feeling at "end of rope", health at risk)***

	CARE GIVING ISSUES TO WHAT EXTENT...					
1	Are you having feelings of being overwhelmed, over worked, and/or over burdened?	1	2	3	4	5
2	Has there been a change in your relationship with your spouse/relative?	1	2	3	4	5
3	Have you noticed any changes in your social life?	1	2	3	4	5
4	Are you having any conflicts with your previous daily commitments (work/volunteering)?	1	2	3	4	5
5	Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?	1	2	3	4	5
6	Do you ever have feelings related to a lack of confidence in your ability to provide care?	1	2	3	4	5
7	Do you have concerns regarding the future care needs of your spouse/relative?	1	2	3	4	5

	FAMILY ISSUES TO WHAT EXTENT...					
8	Are you having any conflicts within your family over care decisions?	1	2	3	4	5
9	Are you having any conflicts within your family over the amount of support you are receiving in providing care?	1	2	3	4	5

	FINANCIAL ISSUES TO WHAT EXTENT...					
10	Are you having any financial difficulties associated with care giving?	1	2	3	4	5

This form should be used in conjunction with the **KCSS Administration and Interpretation Manual** which can be freely downloaded from: www.kingstonscales.ca or **email:** kscales@queensu.ca

 (Jan 2018)

ID # (year of birth followed by first 2 initials of mother's first name):

APPENDIX B

capc Center to Advance Palliative Care

Short Form Zarit Burden Interview (ZBI-12)

	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
Do you feel...?					
That because of the time you spend with your relative that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

→ Short form ZBI-12 validated as screening tool in advanced illness including dementia and cancer
→ Total ZBI-12 score: summation of 12 items (0 to 4 points per item, total score range 0 to 48)
→ Copyrighted, but available for free use by clinicians and for non-funded academic research
→ Suggested guidelines for scoring:

- 0-10: no to mild burden
- 10-20: mild to moderate burden
- >20: high burden

ID # (year of birth followed by first 2 initials of mother's first name):

APPENDIX C

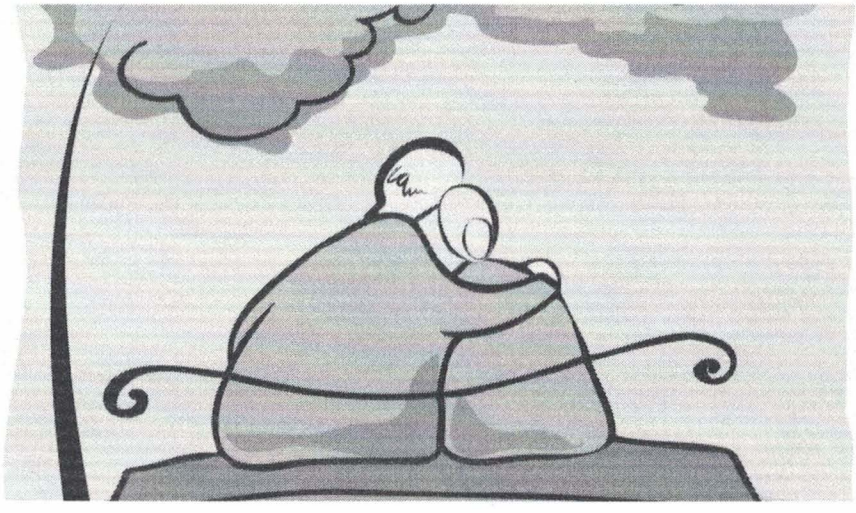
Are you a caretaker for a family member with dementia?

Would you like to be part of a research educational support group run by a Nurse Practitioner?

***Get support from people in a similar situation**

***Learn about dementia and what to expect**

***Discuss strategies to make your life easier**



We will meet for 3 90-minute sessions starting in January 2019

Please contact Brooke Katz, ARNP if interested:

Brooke.katz@gmail.com

Call or text 617-645-4886

APPENDIX D

SEATTLE UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

TITLE: A Psychoeducational Support Group for Family Caregivers of Elders with Major Neurocognitive Disorder/Dementia

INVESTIGATOR: Brooke D. Katz, MSN, APRN, PMHNP, Seattle University

617-645-4886

ADVISOR: Colleen Woolsey, PhD, ARNP, MSN, MA, Seattle University

PURPOSE: You are being asked to participate in a research project that seeks to investigate the effects of a Psychoeducational Support group on stress and burden level in family caregivers of elders with dementia. You will be asked to complete two short surveys before and after the intervention.

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the Doctoral degree in Nursing at Seattle University.

RISKS: There are no known risks associated with this study. However, there may be discomfort as you learn more about the negative symptoms associated with advanced dementia. Information on community mental health resources will be available.

BENEFITS: The results of this study may allow participants to benefit from education and peer support.

INCENTIVES: You will receive no gifts or incentives for this study. Participation in the project will require no monetary cost to you.

CONFIDENTIALITY: Demographic information including age, gender, race, education level, and years of being a caregiver will be collected, but will not be associated with any personal identifying information. Confidentiality cannot be guaranteed in a focus group setting; however, we ask all participants to respect others' privacy and keep all information shared confidential. However, if we learn you intend to harm yourself or others, we must notify the authorities.

RIGHT TO WITHDRAW: Your participation in this study is *voluntary*. You may withdraw your consent to participate at any time without penalty. Your withdrawal will not influence any other services to which you may be otherwise entitled.

SUMMARY OF RESULTS: A summary of the results of this research will be supplied to you, at no cost, upon request. The primary investigator phone number is 617-645-4886. Email: Brooke.katz@gmail.com. The summary should be available in Spring 2019.

VOLUNTARY CONSENT: I have read the above statements and understand what is being asked of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason, without penalty. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any concerns about my participation in this study, I may call Brooke Katz who is asking me to participate, at 617-645-4886. If I have any concerns that my rights are being violated, I may contact Dr. Michelle DuBois, Chair of the Seattle University Institutional Review Board at (206) 296-2585.

APPENDIX E

Dear Stakeholders,

I hope you will support this endeavor to create a psychoeducational support group for family caregivers of elders with dementia. In the community and in assisted living and skilled nursing facilities, family members of those with dementia play a huge role of management and caretaking for the elderly. Because of the complex and severe nature of dementia, caregivers often struggle with self-reported stress and burnout. These feelings can lead to increased medical and psychological costs, as well as decreased quality of life for the caretaker.

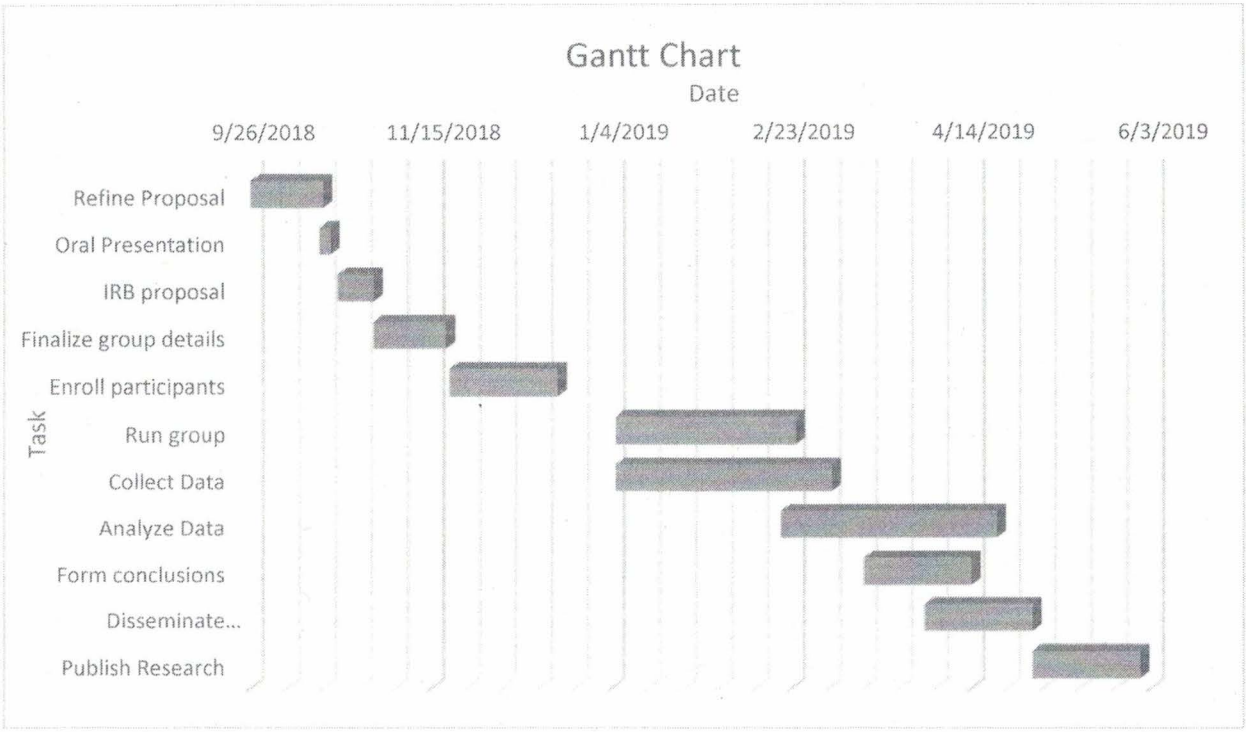
A psychoeducational support group led by an ARNP may be a cost-effective way for family caregivers to collaborate with their peers as well as to learn about the expected course and possible complications that may arouse when caretaking for a family member with dementia.

The costs for this group are minimal and the potential benefits are outstanding.

Thank you,

Brooke Katz, ARNP, PMHNP

APPENDIX F


Gantt Chart
Date
9/26/2018
11/15/2018
1/4/2019
2/23/2019
4/14/2019
6/3/2019
Task
Refine Proposal
Oral Presentation
IRB proposal
Finalize group details
Enroll participants
Run group
Collect Data
Analyze Data
Form conclusions
Disseminate...
Publish Research

APPENDIX G

Session 1:

>Thank members, Explain project and purpose

>inform about confidentiality

>introductions encourage talking/participation

>While every person with dementia is different and changes as disease advances, establishing balance between independence and interdependence leads to confidence and promotes health

***How does your role as "caregiver" effect your role as "family member?"-

>Recommendations from Alzheimer's Association:

-Safety First- stove on, wandering, fall risk-devices, seek higher level of care, support, supervision, violence, destroying property, sun-downing

-Avoid stress, anticipate needs (bathroom, fall risk, food preferences and timing)

-Make positive assumptions (assume that the person can hear you), choices, slow/clear speech

-Create a help signal FOR family members or supports

-Talk it over (give choices not open-ended, loss of control)

-Work better together

***How do you find balance/ what does it look like to you?

>Focus on the person's strengths and how they can remain as independent as possible:

-examples of balancing a checkbook and then reviewing it

***What is important to you for your loved one

-Allow self to experience emotions (denial, fear, stress, anxiety, anger, frustration, grief, depression)

***What do you do for fun?

>Caregiver communication (how to communicate—reminders about delusions, acknowledge and adapt

>Encourage physical activity (seek consult for PT/OT for maintenance plan- restorative to keep active)

>Prepare a balanced diet, protein, avoid alcohol, monitor GERD, dehydration, texture of diet, aspiration, losing weight (could be swallowing issue, avoidance- ST eval)

>Create a daily routine (decreases cognitive demand if there is a routine to depend on- sleep, meals, activities)

>Identify situations which may be too stressful (large groups)

***Define roll, what are some aspects that stress you and how do you deal with that stress?

>Work together

>Get support for yourself:

-connect with other caregivers

-ask for and accept help(mental health support)

-rest when needed

-try not to take things too personally

-allow yourself to laugh

DISCUSSION:

***What kind of support do you have or find helpful

***Anything you would like to hear/talk about.

Session 2: What to expect

>Review updates from session one including review of laws and policies on force feeding

>Behaviors: confabulation, anxiety, depression, withdrawal, yelling, pacing, exit seeking, hitting/grabbing/biting, sexually inappropriate behaviors, falling, refusing food/fluids, laughing inappropriately…

>What to do with behaviors? - cannot fight, acceptance, support, not feel guilty

***What kind of behaviors do you see?

>Medications for dementia include:

-Cholinesterase inhibitors (Aricept, galantamine, rivastigmine), glutamate regulator (memantine), drug for Lewy-body (side effects include nausea/vomiting/diarrhea)

-Other medications to treat symptoms or behaviors (risks and benefits)

-depression/anxiety: SSRIs, SNRIs, Tricyclics, MAOIs,

-sleep: hypnotics, benzodiazepines, melatonin, trazadone, non-pharmacological**

-agitation: SSRIs, antipsychotics, anticonvulsants

***Do you have questions about medications?

>Therapies important at all stages (even end of life). Try to engage, stimulate, anticipate needs

>Occupational therapy: How to make home safer and teach coping behaviors, prevent accidents/falls, prepare you for dementia progression

>Speech therapy: enhance communication, promote safe swallowing and eating

>Diet, plating on non-white dishes (color of white is not seen- sheets, walls, bathrooms), feeding

>Physical therapy: encourage exercise and activity, improve strength and balance to prevent falls, improve cardiovascular health, lessen symptoms of depression, promote enjoyable activities, often people with dementia can ambulate

>For family members as well as those with dementia: mental health care, depression, family members dying, loss

>How it applies to different levels of dementia, depression vs dementia (neurovegetative symptoms)>-How to educate CNAs, how to feed, provide care, at the same time let go of control, person could get angry- don't force

>Adult Day Health: provide respite during the day for caregivers, promote engagement in activity and balanced meals (provides a safe respite but often people have to be continent)

>Assisted Living/Long-Term Care placement: May become indicated in later stages of dementia when behaviors interfere with the ability of the caregiver to safely manage the elder at home.

Provides a safe (can be locked if the person wanders) environment, medication management, nursing care, healthy nutrition, and social engagement.

***What services are you aware of to decrease stress/burden

DISCUSSION:

What do you find helpful?

What are the challenges you face?

Session 3: End of life

>Updates on changes since last group

>Stages of dementia

Seems like most of the family members are in Moderate- severe stage:

Moderate (mid-stage):

-must give up job

-cannot manage money

-cannot drive

-unsafe living alone

-changes in personality (apathetic, negative, pessimistic, suspicious, fearful)

-neglecting personal care (forgetting or refusing)

-isolating

-difficulty in phone conversations

-change in handwriting, unable to write legibly

Severe (late stage):

-danger to self by trying to cook/light candles

-refusing to eat

-refusing medications

-needs help with ADLs

-wandering

-incontinent

-unsteady gait, falls

-agitation, paranoia

-eventually unable to ambulate and or engage in conversation or relationships

What to expect:

- Has difficulty eating and swallowing
- Needs assistance walking and eventually is unable to walk

- Needs full-time help with personal care
- Is vulnerable to infections, especially pneumonia
- If incontinence is an issue, scheduled toileting, limit liquids before bed (but monitor dehydration)
- Use briefs and bed/chair protectors, avoid shame

-What can happen:
-contractures if not moving- ROM exercises
-UTI—change pads frequently
-pneumonia (aspiration)- eat upright, ST consult, keep mouth and teeth clean
-flu- vaccine
-skin tears—careful with moving limbs

Your Role:

During the late stages, your role as a caregiver focuses on preserving quality of life and dignity. Although a person in the late stage of dementia typically loses the ability to talk and express needs, research tells us that some core of the person's self may remain. This means you may be able to continue to connect throughout the late stage of the disease (Alzheimer's Association, 2019)

>music

>reading books or poems or newspaper

>look at photos

>share a favorite meal

>lotion, manicure, massage, brush hair

>go for a walk (garden)

*** How you relate to your loved one and what do you find that works?

>End of life planning:

-In early stages make sure person has a will and advance directives

-DPOA

-POLST

>Role of hospice

>Dementia resources:

Alzheimer's Association (24-hour helpline 1800-272-3900 and website www.alz.org)

www.Alzheimers.net/resources

Camp, Cameron J. (2012). *Hiding the Stranger in the Mirror.* Center for Applied Research in Dementia, Solon, OH.

Coste, Joanne K. (2003). *Learning to Speak Alzheimer's.* Houghton Mifflin Company, Boston.

Mace, Nancy L., Rabins, Peter, V. (2011). *The 36-Hour Day.* The Johns Hopkins University Press, Baltimore.

Power, Allen G. (2012). *Dementia Beyond Drugs*. Health Professions Press, Baltimore.